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Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Report of the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte

Summary

In this report, the Independent Expert on the enjoyment of all human rights by older persons addresses the right to autonomy and care, which she considers to be priority areas. The report provides an overview of the existing international and regional human rights standards and analyses in depth these two key concepts, as well as their scope. This is followed by the Independent Expert's conclusions and a number of recommendations aimed at assisting States in implementing appropriate and effective frameworks that strengthen the autonomy of older persons, ensure their active involvement and participation in all spheres of life and improve their well-being and quality of life, as well as ensuring a human rights-based approach to care settings.

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I. Introduction

1. The present report is submitted by the Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte, pursuant to Human Rights Council resolution 24/20.

II. Activities of the Independent Expert

2. During the reporting period, the Independent Expert visited the following countries: Slovenia, from 17 to 21 November 2014 (see A/HRC/30/43/Add.1); Austria, from 22 to 30 January 2015 (see A/HRC/30/43/Add.2) and Mauritius, from 28 April to 8 May 2015 (see A/HRC/30/43/Add.3). She expresses her appreciation to the Governments of those countries for their cooperation before and during her visits.

3. The Independent Expert has identified elder abuse as a priority area for her mandate, and has participated in a number of events addressing this issue during the past year. On 12 September 2014, she participated in a side event on "Elder abuse and violence against women: a global crisis". The event was organized by the Permanent Mission of the United States of America to the United Nations and Other International Organizations in Geneva on the margins of the twenty-seventh session of the Human Rights Council. In her statement, she highlighted the importance of large-scale research, data and indicators, and legal and institutional mecianisms to tackle elder abuse effectively.

4. She also participated in a side event on the occasion of the United Nations World Elder Abuse Awareness Day on 15 June 2015, entitled "Falling between the cracks: abuse and violence against older women — marking World Elder Abuse Awareness Day—10 years on", co-organized by the Office of the United Nations High Commissioner for Human Rights (OHCHR) and the Geneva NGO Committee on Ageing, with the support of the United Nations Population Fund and several civil society organizations in Geneva.

5. In her statement, the Independent Expert drew specific attention to the recommendations in the Madrid International Plan of Action on Ageing on elder abuse, including against older women, and called for their implementation. She also encouraged further cooperation among all actors to combat all forms of abuse and violence against older persons and to promote the human rights of these persons.

6. Also on 15 June, she participated through a video statement, in a conference on "Tackling elder abuse in Europe: a renewed commitment or a missed opportunity?", which was organized in Brussels by the Council of Europe, the European Commission, AGE Platform Europe and the European Network of National Human Rights Institutions. She highlighted the positive initiatives that had been undertaken at the regional level, and recalling the obligations of Member States, urged them to renew their commitments to ensuring that older persons lived free from abuse and violence in all circumstances.

7. Marking the twenty-fourth anniversary of the United Nations International Day of Older Persons in Geneva, on 1 October 2014, the Independent Expert participated in a side event entitled "Leaving no one behind: promoting a society for all". In her address, she emphasized the need for a holistic approach to protecting and respecting the human rights of older persons to address the challenges they faced on a daily basis.

8. The issue of care is another thematic priority for the mandate holder. In her video message of 8 October 2014, in the context of the Conference on Human Rights of Older Persons in Long-term Care, organized in Brussels by the European Commission and the European Network of National Human Rights Institutions, she advocated for a human rights-based approach for older persons in long-term care, in order to ensure a life of dignity for them. She also addressed the Group of 7 third Global Dementia Legacy Event in

Japan through a statement on 5 November 2014, highlighting the importance of a human rights-based approach when addressing dementia, innovation in care and risk reduction.

9. On 16 and 17 March 2015, she delivered a keynote speech at the World Health Organization's first Ministerial Conference on Global Action against Dementia, held in Geneva. She stressed the importance of considering older persons with dementia as rights holders and States as duty bearers with international obligations to respect, protect and promote human rights. The Independent Expert was pleased to note that, for the first time, States were integrating a human rights-based approach into their call for action against dementia, which was adopted on 17 March as an outcome of the conference.

10. The Independent Expert is mandated to pay particular attention to different groups of older persons, including refugees and climate-displaced persons, as well as persons facing conflict, emergency or disaster situations. On 18 March 2015, she participated in a side event in Geneva on the margins of the twenty-eighth session of the Human Rights Council, on "Building climate resilience: the rights of groups in focus", organized jointly by OHCHR, Displacement Solutions and the Applied Research Association on Justice, Peace and Development.

11. On 11 June 2015, the Independent Expert participated in a follow-up expert round-table discussion on "Climate displacement and human rights" at the Centre for Humanitarian Dialogue, Geneva. In her presentation, she highlighted the fact that older persons were disproportionately affected by climate change, and referred to initiatives that took into consideration the specific needs of older persons, such as the IASC (Inter-Agency Standing Committee) Operational Guidelines on the Protection of Persons in Situations of Natural Disasters, the Peninsula Principles on Climate Displacement within States, and the Sendai Framework for Disaster Risk Reduction 2015-2030, which had been adopted at the Third United Nations World Conference on Disaster Risk Reduction, held in Sendai, Japan, from 14 to 18 March 2015.

12. In accordance with her mandate, the Independent Expert also continued to work in close coordination with the Open-ended Working Group on Ageing, and attended its sixth session, which was held in New York from 14 to 16 July 2015. As a member of the panel on recent policy developments and initiatives concerning the human rights of older persons, she provided an overview of positive initiatives and remaining challenges for the full enjoyment of all human rights by older persons.

III. Autonomy and care

13. It is estimated that by 2050 over 20 per cent of the world's population will be 60 years of age or older. While the increase in the number of older persons will be the greatest and the most rapid in the developing world, Asia is the region with the largest number of older persons, and Africa is facing the largest proportionate growth.

14. In 2011, the Secretary-General, in his report on the follow-up to the Second World Assembly on Ageing, stated:

> With this in mind, enhanced attention to the particular needs and challenges faced by many older people is clearly required. Just as important, however, is the essential contribution the majority of older men and women can continue to make to the functioning of society if adequate guarantees are in place. Human rights lie at the core of all efforts in this regard.[1]

[1] See A/66/173, para. 4.

15. Whereas older persons are often seen as a homogeneous group, this group is in fact the most heterogeneous of all age groups. Some persons may be in good health and may be able to live independently or autonomously throughout their lives; but others will become increasingly dependent on the help of others in old age for several reasons—such as illness, impairments or loss of mobility—and may require varying degrees of specific care.

16. Ensuring that older persons are in a position to lead autonomous lives to the greatest extent possible—irrespective of their physical, mental and other conditions—requires a radical change in the way society perceives ageing. There is a need to foster age-sensitive communities and age-friendly environments to help older persons retain their autonomy and be active, and be integrated effectively in all aspects of life.

17. It is therefore essential to move away from a needs-based and biomedical approach that focuses on disease and functional dependency to an all-encompassing human rights-based approach in which the enjoyment of all human rights by older persons becomes an integral part of all policies and programmes affecting them, including care planning and delivery.

18. Ageist attitudes still persist throughout the world, leading to discriminatory practices towards older persons, including in care settings. Age-based discrimination generates a lack of self-esteem and disempowerment, and undermines an older person's perception of autonomy. This is particularly true when they are in need of care to maintain or regain autonomy.

A. Legal framework

1. Autonomy

19. Autonomy is a core principle of the Convention on the Rights of Persons with Disabilities. Even though ageing should not be associated with disability, this legal framework could be applied to older persons with disabilities and could provide guidance on the scope of the concept of autonomy.

20. The Convention, in its preamble, recognizes the importance for persons with disabilities to have their individual autonomy and independence, including the freedom to make their own choices. Article 3 (a) refers to respect for inherent dignity and individual autonomy, including the freedom to make one's own choices, and the independence of persons.

21. The Convention also refers to autonomy in relation to health care and recovery from violence or abuse. Article 25 (b) requires that health services be designed to minimize and prevent further disabilities, including among children and older persons. Article 19 provides further guidance on measures that should be adopted to facilitate independent living and the full inclusion and participation of older persons with disabilities in the community.

22. The United Nations Principles for Older Persons refer to the principle of independence to describe the importance for older persons to have access to adequate food, water, shelter, clothing and health care, through the provision of income, family and community support and self-help. Older persons should also have the opportunity to find remunerated work or have access to education and training to allow them to live independently.

23. In accordance with the Principles, participation is to be understood as ensuring that older persons are actively involved in formulating and implementing policies that affect their well-being, sharing their knowledge and skills with younger generations, and being able to form movements and associations.

24. The section on self-fulfilment foresees that older persons should be able to pursue opportunities for their full development through having access to the educational, cultural,

spiritual and recreational resources of their societies. Autonomy is referred to in the Principles in relation to care.

25. The Madrid International Plan of Action on Ageing recommends, among other things, taking into account the needs and concerns of older persons in decision-making at all levels, including their participation in the labour market and in voluntary activities, access to knowledge, education and literacy, numeracy and technological training, and to social protection and security.

26. The Inter-American Convention on Protecting the Human Rights of Older Persons, which has recently been adopted and is open for ratification, includes, as core principles, the dignity, independence, proactivity and autonomy of older persons. For the first time, independence and autonomy are explicitly mentioned as rights per se, in article 7. This encompasses the right to make decisions, to determine a life plan, to lead an autonomous and independent life in keeping with traditions and beliefs. Article 11 further specifies the right to give free and informed consent on health matters.

27. Other non-binding instruments include the San José Charter on the Rights of Older Persons in Latin America and the Caribbean, which states in its preamble that the political, public and social participation of older persons is a fundamental human right, as well as respect for their autonomy and independence in decision-making. It also refers, in paragraph 7, to autonomy when addressing the right to free and informed prior consent for any medical intervention, regardless of age, health or treatment. The principle of autonomy is also addressed in reference to the need to create and guarantee the social services necessary to provide care for older persons, taking into account their specific characteristics and needs, and to promote their independence, autonomy and dignity. In paragraph 10, the Charter encourages the improvement of living conditions and environment to strengthen the autonomy and independence of older persons.

28. In Europe, the Charter of Fundamental Rights of the European Union, in article 25, calls on member States to recognize and respect the rights of the elderly to lead a life of dignity and independence and to participate in social and cultural life. In addition, the European Social Charter, in article 23, stipulates the right of elderly persons to social protection, enabling them, among other things, to choose their lifestyle freely and to lead independent lives in their familiar surroundings for as long as they wish and are able, by means of the provision of housing suited to their needs and state of health or of adequate support for adapting their housing.

29. More recently, the Council of Europe, in its recommendation on the promotion of human rights of older persons, made explicit references to autonomy. In particular, it stated that older persons are entitled to lead their lives independently, in a self-determined and autonomous manner. This means, inter alia, taking decisions independently on all issues that concern them, including in relation to property, income, finance, place of residence, health, medical treatment or care, and funeral arrangements.

30. In this regard, autonomy is understood in the Council of Europe recommendation on the promotion of human rights of older persons as including the right to participate fully in social, cultural, educational and training activities, as well as in public life; the right to privacy and family life; legal capacity and the right to receive appropriate support when making decisions and exercising their legal capacity should they feel the need for it, including by appointing a trusted third party of their own choice to help with their decisions and adopt safeguards in order to avoid abuses (see paras. 9-15).

31. The draft protocol to the African Charter on Human and People's Rights on the rights of older persons in Africa uses the term "independence" as a core principle. Article 3 provides that "States parties shall ensure that the principles of independence, dignity, self-fulfillment, participation and care of older persons are included in their national laws and are legally binding as the basis for ensuring their rights". Article 7, entitled "Right to make decisions", contains an implicit reference to autonomy by mentioning that States should

ensure that appropriate legislation exists that recognizes the rights of older persons to make decisions regarding their own well-being without undue interference from family and affiliated groups, and that older persons have the right to appoint a party of their choice to carry out their wishes and instructions.

2. Care

32. Care, in turn, has been referred to as part of the right to social security, including social insurance, and the right of everyone to the enjoyment of the highest attainable standard of physical and mental health. Article 25 (1) of the Universal Declaration of Human Rights states that everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. Articles 9 and 12 of the International Covenant on Economic, Social and Cultural Rights refer to social security, including social insurance, and health care, respectively.

33. The United Nations Principles for Older Persons dedicate a specific section to the subject of care. They include references to family, community and institutional care, access to health care and to social and legal services to enhance the autonomy of older persons. They also stress that older persons should be able to enjoy their human rights and fundamental freedoms when residing in any shelter, care or treatment facility, including full respect for their dignity, beliefs, needs and privacy, and for the right to make decisions about their care and the quality of their lives. There is no reference to the concept of self-care.

34. The Committee on Economic, Social and Cultural Rights interpreted the right to health in an inclusive manner, extending the concept not only to the provision of timely and appropriate health care, but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health.

35. The Committee underlined the importance of the participation of the population in all health-related decision-making.[2] It also recommended that health policies should range from prevention and rehabilitation to the care of the terminally ill,[3] including periodical check-ups for both sexes; physical as well as psychological rehabilitative measures aimed at maintaining the functionality and autonomy of older persons; and attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.[4]

36. The Committee has further emphasized that the growing number of chronic, degenerative diseases and the high hospitalization costs involved cannot be dealt with only by curative treatment. In this regard, States should bear in mind that maintaining health into old age requires investments during the entire life span, basically through the adoption of healthy lifestyles. Prevention, through regular checks suited to the needs of the elderly, plays a decisive role, as does rehabilitation, by maintaining the functional capacities of elderly persons, with a resulting decrease in the cost of investments in health care and social services.[5]

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[2] General comment No 14, para. 11.
[3] General comment No. 6, paras. 34-35.
[4] General comment No 14, para. 25.
[5] General comment No. 6, para. 35.

37. The Committee also noted that national policies should help older people to continue to live in their own homes as long as possible, through the restoration, development and improvement of homes and their adaptation to the ability of those persons to gain access to and use them.[6]

38. In addition, the Convention on the Rights of Persons with Disabilities includes the concept of "universal design", which may be of benefit to older persons. It is defined, in article 2, as the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design and develops State obligations regarding the promotion of the availability and use of universally designed goods, services, equipment and facilities.

39. The Madrid International Plan of Action on Ageing recommends the establishment of preventive and curative care, including rehabilitation and sexual health care, recognizing that health-promotion and disease-prevention activities throughout life need to focus on maintaining independence, on prevention, and on avoidance of delay in disease treatment, as well as on improving the health and quality of life of older persons who already have a disability.

40. Particular actions are encouraged to provide counsel and guide persons on healthy lifestyles and self-care.[7] Detailed actions are designed to further encourage the adoption of care measures that take into account age and the diversity of older persons, including primary care, acute care, rehabilitation, long-term and palliative care, self-care and gerontological services, provided both by formal and informal caregivers. Special attention is given to the importance of developing housing options for older persons that encourage and reduce barriers to independence, including in public spaces, transportation and other services.[8]

41. At the regional level, the African Charter on Human and Peoples' Rights recognizes the right to health and the role played by the family in society, and the right of older persons to special measures of protection in keeping with their physical or moral needs (arts. 16 and 18). The draft protocol to the Charter on the rights of older persons in Africa makes clear mention of care and support and access to health services, including in conflict and disaster situations. For instance, according to article 12, States should identify, promote and strengthen traditional support systems, including medical home based care, to enhance the ability of families and communities to care for older family members and adopt policies and legislation that provide incentives to all stakeholders including adult children, to support older persons in their communities, ensuring that they remain at home for as long as possible.

42. In the Americas, the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights recognizes the right to social security and the right to health (arts. 9 and 10). Moreover, the Inter-American Convention on Protecting the Human Rights of Older Persons dedicates an article to the right of older persons to receive long-term care, while maintaining their independence and autonomy. A comprehensive approach to the right to health has been adopted in article 19, by including health promotion, prevention and care of disease at all stages, including rehabilitation and palliative care.

43. In Europe, the Council of Europe recommendation on the promotion of human rights of older persons dedicates a specific title to care, in which it recommends that States promote a multidimensional approach to health and social care for older persons and encourage cooperation among the competent services. It mentions several measures,

[6] Ibid., para. 33.

[7] Madrid International Plan of Action on Ageing, paras. 67 (d) and 105.

[8] Madrid International Plan of Action on Ageing, paras. 90 (f) and 98-100.

including training, consent to medical care and regulation of care delivery, in home, residential, institutional, long-term and palliative care.

B. Autonomy

1. Definition and scope

44. Autonomy refers to the principle or right of individuals or groups of individuals to determine their own rules and preferences. It includes the freedom and capacity to make one's own decisions and the legal capacity to exercise those decisions. Autonomy encompasses three main elements: an individual aspect, which includes the capacity to make decisions; an economic and financial aspect, understood as self-sufficiency and the ability to generate and receive income; and a societal aspect, which means the existence of communities and environments that are age-sensitive and age-friendly in order to ensure that older persons are able to decide or act for themselves.

45. The full enjoyment of autonomy has broad scope, including not only the right to equal recognition before the law, legal capacity, dignity, self-determination, empowerment and decision-making, but also the right to choose where to live, the right to work, the right to vote and to the right to participate actively in all spheres of society. The denial or restriction of legal capacity directly impacts the autonomy of older persons, as they will no longer be able to exercise these other rights, including making decisions regarding civil, commercial, administrative, judicial or health-related matters concerning their well-being.

46. Autonomy and independence are mutually reinforcing and are often used interchangeably in legal instruments and frameworks. While autonomy refers to the ability to exercise freedom of choice and control over decisions affecting one's life, including with the help of someone if needed, independence means to live in the community without assistance or, at least, where the amount of help does not subject older persons to the decisions of others. In that sense, the concept of independence is broader than autonomy, while autonomy may better reflect the reality of older persons, considering that with age, the need for assistance tends to increase.

2. Legal capacity and equal recognition before the law

47. Various tools exist to measure the degree of physical, cognitive and psychological autonomy, which take into account: mobility, communication and tasks performed on a daily basis to determine the degree of functional and mental autonomy of an older person. In terms of a human rights-based approach, however, the individual aspect of autonomy refers not only to functional autonomy but also mainly to the right to equal recognition before the law and legal capacity. This implies being recognized as a legal person before the law and having the ability to exercise rights as a legal person. Consequently, the will and preferences of older persons are respected, which allows for the exercise of free and informed consent. Older persons should therefore be consulted about and involved in any decision affecting their well-being.

48. Legal capacity is a key aspect of autonomy, allowing older persons to exercise civil, political, economic, social and cultural rights. In circumstances where an older person is partially or completely unable to look after their own interests because of a mental condition, such as dementia, or an extreme state of physical frailty, there may be a need for supported decision making. There is a need to ensure, however, that in such instances a person is not stripped of his or her legal capacity by guardianship measures, which remove their ability to make decisions about certain aspects of their lives. It is important to note in this regard that the Convention on the Rights of Persons with Disabilities provides that a person's status as a person with a disability or the existence of impairment must never be a ground for denying legal capacity. In its general comment No. 1 on article 12 of the Convention, the Committee on the Rights of Persons with Disabilities highlighted that the

Convention does not legitimatize the denial of legal capacity based on perceived or actual deficits in mental capacity.

49. The Independent Expert noted the positive trend in recent years to reform legal capacity and guardianship laws. General comment No.1 also provides guidance to States parties on reforming their current laws and legislation—in particular mental-health legislation that deprives persons with disabilities of their legal capacity—and encourages States to replace regimes that provide for substitute decision-making by supported decision-making.

50. Effective safeguards for ensuring the autonomy of older persons should be developed and implemented to ensure the respect of the rights, wishes and preferences of older persons and to avoid undue interference. The Committee on the Rights of Persons with Disabilities provides guidance on supportive measures, stressing that if, after significant efforts have been made, it is still not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best interests" determinations.[9] In addition, articles 11 and 30 of the Inter-American Convention on Protecting the Human Rights of Older Persons could also guide States on this issue.

51. Legal capacity has particular relevance for older persons regarding making fundamental decisions regarding their social and health care, in particular medical treatment. The respect for and the strengthening of older persons' autonomy in care settings means that they must be able to give consent to, refuse or choose an alternative medical intervention.

52. In his report on the fundamental role played by informed consent in respecting, protecting and fulfilling the right to health, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health highlighted that informed consent is not a mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, safeguarding the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers.[10] Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well-being.[11] Older persons should therefore be encouraged to plan in advance any decisions regarding their care. Advance planning allows them to prevent abuses that often occur in older age.

3. Adequate standard of living and social protection

53. Living with autonomy is closely linked to the right to an adequate standard of living, social security, income security and an adequate public pension. The important role of social protection is recognized in several international and regional instruments and should be fully implemented and enforced in order to promote the autonomy of older persons.

54. Poverty contributes to the decline of older persons' autonomy and is an impediment to accessing adequate nutrition, water and sanitation, and social and health care. Not receiving a pension or not having insurance often inhibits older persons from seeking medical attention, putting them at a higher risk of social isolation and of being denied access to health care. Even for those who have insurance, there are delays in seeking public health care or obtaining prescription drugs because of the financial burden. Financial services, such as loans or mortgages, or insurance are often not available to older persons or are prohibitively expensive because of the inappropriate use of age as a criterion, including for determining risk.

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[9] General comment No. 1, para. 21.
[10] See A/64/272.
[11] Ibid., para. 9.

55. Social transfers and pension schemes often account for the largest part of the resources of older persons and significantly reduce their at-risk-of poverty rate by ensuring some financial security.[12] They are thus an important factor in enabling older persons to live autonomously and not be dependent on intra-family transfers or any other private income. Access to social insurance schemes and pensions, particularly for women, rural workers, and persons who worked in the informal sector, is essential for persons to live an autonomous life when they become old.

56. The Independent Expert strongly encourages the review of austerity measures and fiscal consolidation programmes, especially those which may negatively impact the economic and financial autonomy of older persons by increasing the risk of poverty, exclusion and insecurity in old age. Social protection should be strengthened, both contributory and non-contributory schemes, by increasing resources, improving the availability of and access to services, through communication and by removing any obstacles to receiving the benefits.

4. Right to work

57. It is also important to ensure the right to work by fostering the active economic participation of older persons as long as they are willing or able. Older persons have much to contribute, based on the considerable skills, wisdom, expertise and experience they have acquired throughout their professional life, and they should be encouraged to continue working if they wish. Therefore, workplaces and job options that include older workers should be developed, as well as voluntary work. Older persons have indispensable roles in assisting peers and participating in intergenerational activities by helping younger generations, and by contributing to the education of grandchildren. This will help reinforce social cohesion and the interaction of older persons with other members of the community.

5. Right to adequate housing and accessibility

58. Age-sensitive communities and age-friendly environments are preconditions for older persons to live with autonomy and remain integrated in society. Older persons should be able to live in environments that are safe and adaptable to their personal preferences and changing capacities. The environment should therefore be adapted to their needs. This should include, for instance, outdoor and public spaces, the physical environment, buildings, transportation, social participation and inclusion, civic participation and employment, information and communications and other facilities and services in both urban and rural areas.

59. Physical barriers significantly undermine the autonomy of older persons and deny them access to basic services, including health care. When older persons are unable to drive, the lack of public transport, especially in rural and remote areas, presents serious challenges. Even if they are able to access public transport, older persons still require a reasonable level of physical fitness, the competence to follow bus-route directions, the ability to endure long rides and bus transfers, and a safe environment to wait and to walk in.

60. Accessibility encompasses access to infrastructure, buildings, transportation, information and care settings in urban and rural areas. States should provide comprehensive barrier-free accessibility environments and work towards eliminating existing barriers. Public buildings, facilities, roads and transportation should be easily accessible. For this to occur, revisions to building control acts and urban planning codes, with the inclusion of standards of universal design in a variety of sectors and facilities, may be needed. States should also provide training to all stakeholders involved in adapting public spaces to

[12] A/HRC/14/31.

demographic changes: including engineers, designers, architects, urban planners, transport authorities and conductors, service providers and members of the academic community.

61. Another important element to leading an autonomous life is housing. Older persons have the right to choose where to live, and, to the extent possible, housing should be adapted to their needs. Should they wish If they feel the need to change or adapt their homes because of their mobility requirements. States should secure rent- free accommodation, or at least provide rent subsidies or , credit facilities , to help older persons afford to remain in their own houses.

62. Housing options for older persons, including co-housing based on intergenerational communities, age-adapted homes and flat-sharing concepts should be further developed. Other schemes that include bank credit facilitation, tax incentives and subsidies, involving both private and public sectors should be encouraged so as to build accessible and appropriate housing for older persons. Particular attention should be given to older women and widows, who tend to live alone with no family support.

6. Participation and social inclusion

63. An age-friendly community is one that also considers an older person's political involvement, meaning that age cannot be a justification for any exclusion from decision-making processes and active citizenship. The right to participate in political and public life includes the possibility of being able to vote, and of being elected, sometimes requiring the availability of facilities and materials that are accessible to older persons, including in nursing and institutional care settings. States should provide access to transport to and from polling stations, as well as to attend meetings of public authorities and to participate in trade-union and advocacy efforts.

64. The involvement of older persons in the electoral system has been declining, especially in the age group of 80 and above, as a result of discriminatory practices leading to social exclusion and political marginalization. The participation of older persons should therefore be institutionalized through forums, or consultative, coordinating or advisory bodies at the local, regional and national level.

7. Education, training and lifelong learning

65. Autonomy includes access to education, training and lifelong learning that will help maintain self-esteem and extend knowledge and adaptability to cultural and social changes, especially regarding advances in information technology. The target of educational programmes should not be limited to older persons only, in order to promote inter-generational learning and understanding. States should develop specific pedagogical methods for teaching older persons, such as master's degree programmes in geronto-pedagogics. Particular attention should be given to information technology and computing training programmes.

66. With the rapid evolution of new technologies, autonomy also means having access to the Internet and being able to use information and communications technology and services. When online registration is sometimes the only or easiest way to purchase goods and services, older persons should be able to access these goods and services without depending on others. Older persons constitute a distinct consumer group, with specific needs, interests and preferences. Technologies can contribute to strengthening an older person's autonomy by adapting products to meet the changes incurred with age, such as through adjusting the size of objects or through offering technical support.

67. Autonomy also means being able to access cultural activities through the availability of transport, subsidized tickets for cultural activities and reduced fees or free entrance for older persons. Services such as closed-captioning and open subtitled for those with hearing impairments should be provided in theatres, museums and other cultural-related facilities.

8. Right to health

68. In care settings, autonomy means that older persons are able to participate in the formulation, monitoring and evaluation of their care services, as well as in clinical trials in order to determine the effect of medication.[13] Older persons should no longer be seen as passive recipients of care but as active users.[14] This change of paradigm from passive to active care is a shift from care provided for people to care provided with people.[15]

69. Older persons should receive health education, and information on the social and health-care services available to them, on their rights in care settings. They should also receive guidance on adequate nutrition and on different pathologies, including communicable and non-communicable diseases. In this context, self-care can help older persons to participate actively in and manage their own health.

C. Care

1. Definition and scope

70. There is no universally accepted definition of care.[16] Care aims at maintaining or regaining the optimum level of physical, mental and emotional wellbeing and to prevent or delay the onset of disease. While a distinction is generally made between social and health care, depending on where and by whom such services are provided, care should be understood in a complementary and integrated manner for the benefit of older persons. It comprises a range of services, facilities, knowledge and support aimed at increasing the individual's physical, mental and social well-being, provided either by formal or informal carers, and through the public or the private sector.

71. Care encompasses services such as assistance with the activities of daily life, social income, protection and security, as well as health promotion and disease prevention, treatment and rehabilitation and the provision of primary, secondary and tertiary health care, in ambulatory, institutional or home settings. Equality of access to social and health care throughout the life of older persons is also the basis of an autonomous life and active and healthy ageing.

2. Care settings

72. Home and family care is the most common form of care for older persons in many countries, where care of older persons is regarded very much seen as the responsibility of the family. While for many older persons, family care is the preferred option in old age, there is a need for adequate parallel support to family members and other informal caregivers. This would include respite care services, needs assessment, counselling and advice, self-support groups and practical training in care-giving, as well as information about measures to protect carers' own physical and mental health, weekend breaks, and integrated planning of care for older persons and families. Including family carers into the social security system is particularly important given that caregivers are often women who are not gainfully employed and in view of the increasing need for care in ageing societies.

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[13] See A/HRC/18/37, para. 16.

[14] Economic Commission for Europe policy brief on ageing No. 15, "Innovative and empowering strategies for care" (2015), p. 5.

[15] Ibid.

[16] World Health Organization glossary of terms for community health care and services for older persons (2004). The glossary (www.who.int/kobe_centre/ageing/ahp_vol5_glossary.pdf) could provide guidance on the scope of "social care", "health care", "acute health care", "ambulatory care", "long-term care", "home care or domiciliary care", "adult care homes", "day care centres", "hospice care", "palliative care", "residential care" and "formal and informal caregivers".

73. The Independent Expert emphasizes that the assistance provided by family members and communities cannot substitute for States' obligations to promote and protect all human rights of older persons. She also notes the radical changes some societies are undergoing, such as changes in family patterns or lifestyles, as well as challenges related to migration and urbanization, which need to be taken into account.

74. The institutionalization of care, while it can be the result of an autonomous decision of a person as he or she becomes older, can often take the form of forced institutionalization and compulsory placements, especially when no other forms of care are available for the individual or when relatives are unable or unwilling to provide care.[17] When proper legal and institutional mechanisms and procedures are in place in care settings, thus ensuring freedom of choice and informed consent, older persons in need of care can lead a life with dignity. It is therefore crucial to ensure older persons' autonomy, in particular when it comes to any decision-making affecting their care.

75. Flexible and open care institutions have been established in several countries in order to avoid such institutionalization, with free provision of medical home care, including administration of medication and infusions. Such services have improved the quality of life of older persons by enabling them to stay at home.

3. Quality control and accessibility

76. Ensuring quality control in care settings is one of the main challenges. It has been pointed out that the office hours of social and health-care services were often anti-social and to the disadvantage of older persons. For example, older persons are often required to arrive early in the morning and queue to receive a number that will correspond to their attendance. Such an approach results in long waits in uncomfortable and even inhumane conditions, with a lack of appropriate assistance that takes into account their specific needs. Associated with this, is the shortage of social and health-care professionals with formal education in geriatrics and gerontology, and with gender and disability-based expertise.

77. Most health-care undergraduate programmes do not include geriatric and gerontology in their curricula, with the result that health-care professionals are not fully trained to help and understand older persons. For older persons who do not have family or community support, having to rely exclusively on formal caregivers without such training or qualifications can make their lives particularly difficult.

78. The fragmentation of care also causes problems owing to the co-existence of many units that are not integrated into the network of services, and which results in hours spent in filling complicated forms to access both social and health-care services and facilities. It also results in poor quality service provision, inefficient use of available resources and low user satisfaction. This may often be due to the lack of coordination between the different levels and places of care, especially in hospitals. Consequently, older users experience a lack of continuity in care, together with a lack of consistency in the provision of services for meeting their needs.

79. Equitable access to health services is another challenge faced by many countries. Care facilities, goods and related services need to be made available, accessible, affordable and acceptable, and be of good quality for all older persons. There is a need to ensure that these all older persons have access to the same services irrespective of the type of care and the place of residence, including in urban, rural and remote areas. In this connection, older persons may require access to transportation, information and communication on care-related programmes and facilities that meet their requirements and needs.

[17] See E/2012/51, para. 25.

80. Care work is often characterized by a heavy workload, long working hours and emotional exhaustion; and care workers tend to be undervalued, underpaid and undertrained. There is evidence that the satisfaction of persons receiving care correlates with the well-being of their care workers.

4. Elder abuse and violence against older persons

81. Abuse of and violence against older persons in home and institutional care settings, by both formal and informal caregivers, is still a taboo subject in many countries and an underreported problem. These older persons may be subjected to intimidation, aggression, inappropriate behaviour-control methods, negligence, or a failure to provide the appropriate or necessary care, among other forms of ill-treatment.

82. Risk factors for abuse and violence in care settings may relate to institutional aspects, such as poorly trained staff, also as a result of a lack of career prospects and high turnover, as well as a culture of tolerance of aggression towards patients.

83. Regular inspection and monitoring of home visits by certified care workers is necessary to ensure adequate quality of care and the protection of older persons, including against physical and mental violence, and from degrading treatment and neglect.

84. Certain countries have implemented technical services provided by public prosecutors to help older persons who are involuntarily hospitalized or involuntarily receiving medical treatment. Offices of an ombudsperson have also been created to support older persons in expressing their needs and decisions, and to seek remedy.[18] In care facilities, committees composed of older persons have been put in place to supervise and evaluate the quality of the services, especially regarding food, hygiene and interaction with staff.

5. Geriatric services and palliative care

85. Older persons have different patterns of disease presentation than younger adults, they respond to treatments and therapies in different ways, and they frequently have complex social needs that are related to their chronic medical conditions. It is therefore important to ensure that sufficient doctors, staff and others qualified in geriatric health are available to ensure that these older persons can fully enjoy their right to health.

86. Particular attention needs to be given to palliative care. In certain countries, this is not officially recognized as a medical speciality and the medicine used in such care is limited, for several reasons, including restrictive drug regulations, failure to implement a properly functioning supply and distribution system, and inadequate health-care system capacity.

87. The Independent Expert stresses that the Special Rapporteur on the right to health and the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment qualified the failure to ensure access to controlled medicines for the relief of pain and suffering as a threat to the fundamental right to health and the right to be free from cruel, inhuman and degrading treatment.[19]

6. Groups in focus

88. Particular attention should be given to specific groups of older persons when designing and implementing care policies, goods and services, in particular older women,

[18] Economic Commission for Latin America and the Caribbean. *Autonomía y dignidad en la vejez: Teoría y práctica en políticas de derechos de las personas mayores*, pp. 82-83. Available from http://repositorio.cepal.org/bitstream/handle/11362/37523/S1421014_es.pdf?sequence=1

[19] A/HRC/22/53.

older persons with disabilities, and persons with chronic illnesses, non-communicable diseases and dementia. Gender, disability and cultural sensitivities should be promoted in care settings to allow older persons from different backgrounds to be informed effectively and to be able to make decisions. Specialized integrated social and health-care services should be developed and implemented to address dementia and other degenerative diseases that lead to dependency.

IV. Conclusions and recommendations

A. Conclusions

89. **In the light of the intensity of ageing in many societies, there is a need to ensure that older persons are enabled to lead autonomous lives. This also calls for a paradigm shift that focuses on the inclusion of older persons in society at all levels, encompassing age-friendly communities and environments, as well as people-centred models of care, and that promotes the autonomy and dignity of older persons.**

90. **The design, implementation, monitoring and evaluation of any social and health-care legislation, policies, programmes, strategies and settings must take into account the respect for and the strengthening of older persons' autonomy. To promote this autonomy, effective care for older persons needs to integrate economic, physical, mental, social, spiritual and environmental factors.**

91. **The increasing prevalence of chronic and degenerative diseases in older age poses challenges to the development and implementation of appropriate models of care for older persons. The disease-focused approach in care at different levels needs to be replaced by more effective and rights-based models in order to address the specific needs of the most heterogeneous of all age groups.**

B. Recommendations

92. **With a view to assisting States in developing and implementing appropriate and effective measures to ensure the autonomy of older persons, including in social and health-care settings, the Independent Expert makes the recommendations set out below.**

Legal, institutional and policy framework

93. **States must fully comply with their international obligations relating to autonomy and care. The Independent Expert strongly encourages States to ratify all the core human rights treaties, including the Convention on the Rights of Persons with Disabilities, as well as all relevant regional instruments —notably the recently adopted Inter-American Convention on the Human Rights of Older Persons, which makes explicit reference to autonomy and care.**

94. **States should design and implement effectively national policies and action plans on ageing that include specific provisions on autonomy and care, in a comprehensive and intersectoral manner.**

95. **States should establish national councils on ageing, with older persons among its members, to design and develop policies, including care, that correspond to their needs and respect their autonomy. Such councils should guarantee pluralism, represent the diversity of older persons and receive sufficient funding so that they can function properly and effectively.**

Study and statistics

96. **States should ensure, nationwide, systemic and regular collection of disaggregated statistical data, and carry out studies to assess the situation and needs of older persons and develop targeted policies for older persons. Data must be used sensibly to avoid stigmatization and potential misuse. Particular care should be exercised when collecting and analysing data in order to respect and enforce data protection and privacy. Older persons, including the very old and those in institutionalized care settings, should systematically be included in surveys and official statistics, in order to ensure a better differentiation for age and to better reflect the broad heterogeneity of older persons.**

97. **States should constantly conduct researches and studies and collect age- and gender-disaggregated data on abuse and violence against older persons in and outside care settings in order to assess the current situation and take appropriate measures to tackle elder abuse.**

Discrimination, abuse and violence

98. **There is a need for national anti-discrimination strategies addressing discrimination in a coherent and multifaceted way. States should, through legislation, prohibit direct or indirect discrimination against older persons, including in the financial and insurance services sectors, as well as in care settings.**

Legal capacity and equal recognition before the law

99. **The Independent Expert emphasizes that supported decision-making for persons with intellectual or psychosocial disabilities, including older persons, is essential for the respect of the autonomy of older persons and their individual rights, in their own capacity to give and withdraw informed consent for medical treatment, to access justice, to vote, to marry, to work and to choose their place of residence. Judges should be guided by the objective of ensuring that older persons can lead a self-determined and autonomous life for as long as possible.**

100. **Older persons must be provided with guarantees to ensure that their preferences, their will and their best interests are taken into consideration in all matters relevant to their life, including treatment, residence or assets. Conflict of interest and undue influence should be regulated, especially in reference to family members and caregivers.**

101. **Safeguards to free and informed consent should be adopted through legislation, policies and administrative procedures in conformity with international and regional standards. Particular attention should be given to illiterate older persons or persons with less formal education.**

Adequate standard of living and social protection

102. **States must recognize the human right to social security in domestic law. Non-contributory and contributory pension schemes must be guided by international human rights standards for the right to social security.**

103. **States should put in place social-protection and poverty-reduction programmes, particularly designed for older persons, including those with disabilities. Human rights principles and standards should be integrated throughout the design, implementation and evaluation of social pensions, thereby ensuring that older persons fully enjoy their human rights.**

104. **The Independent Expert recalls that the right to social security includes both contributory and non-contributory benefits and benefits both in cash and in kind, and that benefits should be adequate in amount and duration and accessible to all without**

discrimination. Non-contributory old-age benefits or other assistance should be provided for those without resources on reaching old age, with special attention to be given to older persons working in the informal sectors, older women, older widows, and those living in rural and remote areas.

105. In the light of the significant contribution of social transfers and pension schemes, austerity measures and fiscal consolidation programmes should be revised in order to ensure the provision of basic income to older persons, together with adequate social and health-care services and support.

106. A thorough evidence-based analysis of the current and future needs of various forms of care or affordable, accessible and barrier-free housing is essential for meeting the immediate needs and for planning and preparing for the future and for developing appropriate measures to ensure an inclusive society for all ages.

Right to work

107. States should introduce incentives for employers and employees to extend people's working lives beyond the mandatory retirement age. Workplace environments and working conditions should be adapted to older workers by introducing flexible working arrangements, including phased retirement. The Independent Expert also points out the importance of continued education and access to new technologies, as well as vocational rehabilitation. States should ensure that social security and pension systems do not penalize older workers who choose to work beyond normal retirement age.

108. The contribution of older persons should be recognized and encouraged, including, but not limited to, their role in the care of family members, in household maintenance and in voluntary and associative activities.

Right to adequate housing and accessibility

109. States should adopt housing policies that take into account the special needs of older persons to enable these persons to live autonomously. Ageing at home requires innovations in the housing sector, including alternative forms of housing for older persons, such as mixed and designated communities and age-adapted homes, or flat-sharing concepts that promote intergenerational interaction. Alternative forms of housing and the possibility to adapt their homes should ensure that older persons can remain in their homes and lead autonomous lives.

110. States should establish tax incentives and subsidies to encourage developers to build accessible and appropriate housing for older persons. Credit facilities should also be encouraged in public and private banks to allow older persons to adapt their homes or to become homeowners. In view of the difficulties often faced by older persons in accessing financial and insurance services and resources, the Independent Expert wishes to remind businesses of their obligations to adhere to international standards preventing, inter alia, all forms of discrimination and to the Guiding Principles on Business and Human Rights, which provide guidance on responsible contracting and State-investor contract negotiations.

111. Given that the physical ability, individual characteristics and the transport environment crucially influence the mobility of older persons, States are encouraged to adopt comprehensive national accessibility policies. There is also a need to include mandatory provisions demanding the implementation of barrier-free access. States should also ensure the elimination of existing barriers in public spaces and buildings, including in care settings. The Independent Expert recommends that architects and engineers apply a human rights-based approach in designing public and private buildings.

112. States should ensure older persons' mobility, including affordable and accessible public transport, both in urban, rural and remote areas. This could encompass free or discounted transport, low-floor buses and trains, and facilities to help older persons purchase tickets online or in person.

Education, training and lifelong learning

113. The promotion of lifelong learning is essential for older persons to be able to deal with constantly changing circumstances, requirements and challenges, for their active participation in society and for an autonomous life continuing into old age. The specific needs of older persons should be taken into account in the planning and design of educational offers.

114. Distance learning and digital training should be offered to older persons in order to bridge the gap among generations and avoid dependency on others as a result of to the lack of knowledge of information and communications technology.

Care

115. States should improve coordination among sectors throughout the continuum of care, from prevention, promotion, rehabilitation, through to long-term and palliative care, including social care and other community services, and prevent unnecessary institutionalization. Universal coverage and uniform national legislation should be introduced in order to avoid fragmentation of social and health services.

116. Older persons should be included in the design, planning, implementation and evaluation of care, be these social or health-related services and facilities. Gender, disability and cultural-sensitivity programmes should be integrated in every care setting in order to take into account the diversity of older persons and meet their requirements and needs.

117. States should provide assistance to families and to other informal caregivers. This should include human rights, medical and human resources training, counselling, and financial, social and psychological support. States should strengthen mechanisms to officially recognize the work undertaken by informal caregivers, including, as appropriate, work permits that allow flexible schedules in order to combine paid work with informal care of older persons, as well as their inclusion in the social security system. Particular attention should be given to older women in their role as caregivers.

118. States should develop national home-care programmes and community-based care services, in rural and remote areas alike. Such programmes and services should be designed and implemented in consultation with the older persons themselves and their families.

119. States should provide long-term care through a comprehensive and intersectoral approach, and promote the transfer of older persons from an institutional to a community-care residence and home, if the older person so wishes.

120. States should develop training programmes to improve the self-care of older persons. Older patient education may include health education and awareness of pathologies, thereby increasing self-esteem and confidence.

121. As forced institutionalization violates the rights of older persons, States should revise their legislation and regulations, in particular with regard to mental health-care settings. A clear set of standards should be established on free informed consent in care settings, in particular in mental health-care settings.

122. Residential councils that include older persons should be established in institutional care settings to promote the active participation of these persons in the organization of their own daily activities.

123. States should establish quality monitoring and effective and transparent accountability mechanisms for public and private care settings, which take into account older persons' assessments and evaluations. This requires establishing clearly defined benchmarks, such as codes of practices and conduct, and where conformity can be assessed and verified by sufficient and well-trained staff both in home and institutionalized care settings.

124. Quality care is also correlated with the working conditions and well-being of care workers. In order to ensure that care workers provide care that meets the emotional and physical needs of older persons with compassion and dignity, and in order to attract people into the care sector and retain them there, better training opportunities, including academic qualifications, should be provided. This, in turn, will also help portray care work as a profession with good career prospects.

125. Given the multidimensionality of abuse and violence against older persons, there is a need to adopt a comprehensive, integrated and inclusive approach involving different disciplines, organizations and actors, as well as older persons themselves, in identifying appropriate responses to abuse and violence.

126. States should adopt legislation and policies to prevent, detect, investigate, prosecute and criminalize elder abuse. Procedures must be in place for reporting abuse and violence, including in public and private care settings. The Independent Expert calls on States to pay particular attention to protecting victims from retaliation, especially in cases where the abuse or violence is committed by a family member, relative or is the result of an intimate relationship.

127. Collective prejudice against older people and general public awareness influence the way in which abuse and violence is perceived, recognized and reported. States should devise an awareness-raising strategy regarding the issue of abuse of and violence against older persons. Awareness-raising campaigns should not only target older persons themselves, but also their social environment, such as family, friends and caregivers. They should also target employees in homes and institutions, doctors, nurses and caregivers and the broader communities.

128. Information about remedies, referral pathways and available services should be made widely available to older persons and the broader public domain, and particularly the social environment of older persons. Dissemination of information to older persons about their rights could help to further improve disclosure about abusive experiences and make more effective the implementation of laws related to elder abuse when such laws exist. Caregivers and law enforcement personnel should receive training to recognize and handle cases of abuse and violence against older persons.

129. States should develop ombudsman-like positions inside institutionalized care settings that could improve older persons' care and quality of life and denounce cases of abuse and violence, including health-care fraud.

130. Older persons have different patterns of disease presentation from younger adults, they respond to treatments and therapies in different ways and they frequently have complex social needs that are related to their chronic medical conditions. States should therefore ensure the availability of geriatric and gerontological specialists in different types of care services and facilities. There is a need to further promote geriatric medicine to ensure that a sufficient number of qualified geriatrics are available to meet the needs of an ageing society.

131. **The right to palliative care should be enshrined in the legal framework so that older persons can enjoy the last years of their lives in dignity and without unnecessary suffering. States should ensure the availability and accessibility of palliative care for all older persons in need, particularly those who suffer from a life-threatening or life-limiting illness. Training, and adequate and affordable medication and therapeutic measures, should be provided in public and private care settings.**

132. **Innovative care for older persons with chronic and degenerative diseases, such as dementia, should be encouraged through public and private partnerships, including scientific and academic sectors, in order to improve the quality of life and well-being of those affected.**